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ABSTRACT

A series of individual and small-group interviews on self determination for individuals with disabilities was conducted as part of the Vermont Self-Determination Project, a 3-year project to implement a statewide system change designed to allow people with developmental disabilities to have control and choice in their lives. The interviews were held with four teams, each composed of a consumer, a family member, and a service agency representative. Additional interviews were conducted with non-team project staff. Results from the interviews indicated that: (1) an important component of self-determination is individual control over lives and money; (2) self-determination must go hand-in-hand with the further development of self-advocacy; (3) it is important that agencies, families, and others work with teams to further support the growth of self-advocacy; (4) clarity is needed on areas of responsibility for individuals who elect to manage their own money through an intermediary service organization; (5) quality-of-life issues need to be examined within the context of self-determination; and (6) real choices are limited within the existing system. Success and challenges of the project and the self-determination teams are discussed. (CR)

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"LEARNING COMMUNITY"

DISCUSSION PAPER:

SELF-DETERMINATION IN VERMONT

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SELF-DETERMINATION IN VERMONT

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"Learning Community" Discussion Paper:

Self-Determination in Vermont

Introduction

This paper was generated as part of a "learning community" between the Vermont Self-Determination Project, funded by the Robert Wood Johnson Foundation, and the Center on Human Policy. The purpose of the 3-year project (January 1997-December 1999) is to implement statewide systems change that will allow people with developmental disabilities to have real control and choice in their lives.

The intent of this learning community is to serve as a forum for discussion of issues and lessons related to implementation of self-determination in Vermont. The learning community was designed as a process, to occur over the course of the 3 years, which would include some time for group discussion, as well as some written reflections based on individual and small-group interviews.

This particular paper is based on a series of individual and small-group interviews that occurred during May-June 1998. It, thus, represents feedback about the project at that point in time, rather than developments that have occurred since then. This paper was drawn primarily from interviews with the project's four regional teams, each composed of three people--a consumer, a family member, and a service agency representative. We also conducted interviews with some additional non-team project staff, and some Division staff. Finally, at the time, partly because the project was still in the early stages of its implementation, we were able to schedule interviews with only a very limited number of consumers, family members, guardians, agency representatives,

and others. Thus, this paper does not present broad-based perspectives on issues from these points of view. At the same time, we anticipate that a later learning community activity will involve gathering more in-depth perspectives from these groups.

At the time of our interviews, the focus of the project's work had been: (1) creation and development of the teams; (2) team and project outreach; and (3) identifying and addressing barriers to the implementation of self-determination. All of this involved a tremendous amount of work, some of which was anticipated and some of which was unforeseen until issues arose based on beginning implementation of the project.

The paper is organized into several topic areas. Within each of these areas, themes or lessons that arose from the interviews are discussed, followed by successes and challenges.

What is Self-Determination?

We began all interviews by asking people what the term "self-determination" meant to them. They responded with thoughts about the term itself, as well as about the idea of a "self-determination project."

Self-determination is about having control over your life. When asked what self-determination means to them, people talked about things such as "having one's voice be heard," "getting a life," "figuring out what you want and going for it," and "having a say over your life." Being "in control of your money" was seen as an important component of self-determination. And, it was seen as something that posed a significant threat: "It's a shock to me how much of a threat this has been--to agencies,

individuals, parents, home providers--money is power...and the thought of shifting that has gotten people riled up."

There was widespread agreement that control of money involved, at least, being informed about what money is available and in charge of decisions about how it is spent. At the same time, most people saw self-determination as something that involves a range of degrees to which people may want to actually manage their money and services. It has been helpful for some of them to think about this in terms of "consumer-managed" versus "consumer-directed" services. They believe that self-determination should aim toward assisting people to direct their own services, and at the same time give people a range of options for money and service management. Some individuals may choose to manage their own money and services, perhaps with the assistance of family or friends, and others may ask a service agency to be involved in this.

At the same time, two key points were that: (1) There are limitations to control of money within the system. For instance, a person cannot receive a check from Medicaid at his or her home; thus, if a person wants to manage his or her own money, this money still must be channeled to the person through a designated agency (one agency in each region of Vermont is a "designated agency," with overall responsibility for ensuring that needed services are provided within the region to adults and children with mental health, behavioral, emotional, and developmental disabilities) and/or a fiscal intermediary. (2) Money is important only in a larger context of self-determination, where self-determination is associated with broader issues of empowerment.

Self-determination is about much more than any one project. People felt it was important to stress that self-determination in Vermont did not begin with this project and is not confined to this project. At the same time, they feel that this project will make a valuable contribution to promoting and expanding opportunities for self-determination in the state.

Successes and Challenges

1. A strength of the project is their broad definitional approach to the term "self-determination." In this way, they leave room for self-determination to be defined from the perspective of people with disabilities. At the same time, there are certain challenges associated with broad definitions. For instance, one person asked, "How will we know when we are doing it? How will we know what success is?" This person speculated that "over time, maybe we'll be able to see this more clearly."

2. People questioned how control over money fits with other things essential for a high quality of life. Some of the initial experiences of the project's involvement with people focused predominantly on control of money. It was significant that project staff took advantage of this opportunity and began identifying limitations to control of money, and working to address systems issues that needed to be resolved in order to help people gain more control of their money and manage it if desired. At the same time, this problem solving was taking significant time and energy. There was concern among some people involved with the project that a large amount of energy had been focused

on money, and they hoped at least an equal amount of project energy would be devoted to helping people in other areas of their life such as relationships, meaningful days, transportation, and so forth.

Past Experiences of Self-Determination in Vermont versus the Present Opportunity

We asked people what, if any, opportunities there had been up to this time for any degree of self-determination within Vermont. In addition, we asked their speculations on how the project might make a difference in increasing opportunities for self-determination.

Up until now, self-determination has occurred in small pockets throughout the state. In the past, there has been some opportunity for people in Vermont to practice at least some aspects of self-determination (e.g., to direct one's own services to some extent, though not to manage them). However, there was general agreement that these opportunities were hit and miss, occurring within some "pockets of excellence" or for those who managed to have their voice heard, and that self-determination has been mostly just given lip service rather than widespread implementation in the past.

This project provides an important opportunity to make self-determination, as a universally accepted option, a reality within Vermont; but this will only happen if everyone works together. There is the sense that this project has the potential to play a major role in making self-determination a statewide reality. At the same time, it is felt that this will only succeed if everyone works together on this--the state Division of Developmental Services, the providers, self-advocates, families, and others.

The project was conceived with recognition that collaboration (e.g., of the teams, and other project staff) with provider agencies, including their administrators, was essential. Thus, part of the initial grant proposal to the Robert Wood Johnson Foundation entailed involvement of the agencies in a statewide network promoting education, discussion, and problem-solving on issues related to implementation of self-determination.

In the early part of the project, there had been some positive contact and interaction between some of the teams and selected agencies, but people were still unsure whether or how the network would come together in a way that promoted a sufficient degree of collaboration. People had questions about this for a number of reasons:

- Some of the initial contact between teams and agencies was more contentious than collaborative, as they struggled to work through issues (e.g., of budgeting, liability) for the first time on complex situations.
- Some project staff sensed that agency staff were nervous about upsetting administrators or even potentially loosing their jobs if they expressed a desire to refer someone to the self-determination project.
- At the outset of the project, the vast majority of the project coordinator's time and energy was spent developing the teams, with relatively little left for cultivating connections between the project and the agencies.
- Also, at the outset of the project, there was not as much participation of agency staff, particularly administrators, as hoped for in project training

sessions and other activities, which were envisioned as a vehicle to bring network members together. Some of these training sessions were highly oriented toward a project staff with widely differing knowledge bases vis-a-vis various systems issues; thus, some people who were interviewed speculated that lack of participation was due to a feeling that they already knew what was being presented at the meetings.

- Provider agencies still did not all have a lot of information about the self-determination project, and, at the same time, were busy preparing for impending system-wide restructuring to take place.

There is the need for self-determination to go hand-in-hand with the further development of self-advocacy. Recognizing that a circle of support would be important for those who were pursuing self-determination, it was determined from the outset of the project that people who the teams worked with would need to have a support network in place, and that project teams should not themselves serve as people's support circle. While having a support circle was not part of the eligibility criteria listed in the Vermont Self-Determination Project Policy Guidelines, it was specified in these guidelines that teams would not act as someone's support circle, but would assist someone to pull a circle together.

Based on feeling that, in the past, those who got more choice and control in their lives were those who had the strongest voices and support networks, some people wondered how self-determination would work for people who do not have stable, strong circles of support. They suggested that one way to address this is to ensure that there

is a simultaneous focus on expansion and development of self-advocacy throughout the state. As one person put it, "The strength of self-determination depends on the strength of self-advocacy. The self-advocacy movement has to get stronger for self-determination to get stronger." In the initial stages of the project, the teams were already beginning to form connections with and serve as a resource to local self-advocacy groups, and were committed to having this be one of their priority activities.

Successes and Challenges

1. It was suggested that one of the markers of success of this project will be that, at the end of 3 years, everyone in the state will perceive that they have an opportunity for self-determination. Self-determination will be "on the menu" for everyone, and will not depend as much on "getting one's voice heard." A success of the project is that the teams had begun to do considerable outreach, and the project as a whole was becoming a very visible presence in the state.

2. There is a history in Vermont of significant collaboration between different constituencies. People have worked together to close the Brandon Training School, and to develop services that are highly responsive and individualized. A strength of the project is that continued collaboration was recognized as key to the success of this project. From the start, the project has involved significant collaboration from many different constituencies, at all levels of the project (e.g., from funders to project staff and team members).

At the same time, project staff and others were clear that the success of the project, and ultimately of self-determination more broadly, would depend on the full

collaboration of the everyone, in new and different ways than in the past. This will entail the creation of new roles and relationships between self-advocates, family members, service providers, the Division, and others. This will have to be demonstrated, over time, in at least four ways: (1) everyone truly listens and responds to people with disabilities; (2) agencies, including both staff and administrators, show that they are truly willing to work with self-advocates, families, teams, and others, with an openness to "thinking outside of the box," and giving support and encouragement to staff who pursue creative ideas; (3) families, advocates, and self-advocates will need to recognize and support agencies that demonstrate good-faith efforts to develop creative alternatives; and (4) the Division will need to (a) support families, advocates, and self-advocates, particularly in the face of agencies that may be unresponsive, and (b) give support and recognition to agencies that are demonstrating good-faith efforts to think and work creatively.

3. Expansion of self-advocacy will be one safeguard against people having no voice. Through its activities, the project has made a significant contribution to leadership training for self-advocates. It is also key that the project as a whole has, from the start, worked in collaboration with the Vermont Peer Support Network; and that project teams have made connections with individual self-advocates, and self-advocacy groups, and that they consider this a priority in their work.

In the future, it will be important that agencies, families, the Division, and others work with teams to further support the growth of self-advocacy. This work needs to include: (1) expanding opportunities for leadership training for self-advocates; (2)

increasing the numbers of people who serve in an advisory and support role for self-advocates and self-advocacy groups; and (3) increasing the outreach, beyond those currently involved in self-advocacy, in order to assist people to develop the support networks or other resources that may be instrumental in facilitating their access to opportunities for self-advocacy and self-determination.

At the same time that initiatives are undertaken to help give people with disabilities more voice, it is important to keep in mind that there are some individuals who will always be reliant on the assistance of others to have their voice heard. Related to this, a challenge is to ensure that those who assist do not promote their own agenda rather than that of the person they are assisting. A safeguard against this is the involvement of a number of people, as a circle or network of support.

Self-Determination and Systems Issues

Our interviews occurred just before the implementation of system-wide restructuring. Prior to restructuring, the primary responsibility for financial decisions and quality assurance was located at the Division; insurance provision (e.g., liability, workers' comp, unemployment insurance) was the responsibility of certified agencies (either designated agencies or other agencies that provide state-funded supports). Following restructuring, financial decisions, as well as quality assurance responsibilities, were to be located at the designated agencies; certified agencies would retain insurance responsibilities.

In addition, prior to implementation of the self-determination project, money flowed from the Division to the designated agencies in each region, who provided

services or contracted with others to provide services. Soon after the project began, project staff became involved in the creation of an intermediary service organization (ISO), to serve as a fiscal intermediary (e.g., disbursing funds according to the budget created by the person and his or her circle). For those wanting to manage their own money through the ISO, it was not yet clear whether money would still flow from the Division to the designated agencies, and then to the ISO, or whether it could go directly from the Division to the ISO.

There was a great deal of uncertainty, speculation, and some anxiety about what the exact nature of changes in these areas would be, and the impact that this would have on self-determination. In particular, there was uneasiness about the following issues:

- Will designated agencies be able to make unbiased financial decisions when they are also themselves service providers?
- Who will have liability and cover insurance for people who manage their money through an ISO, and how will that be determined?
- How will money flow (e.g., for people who manage their money through an ISO, will the money first have to go through a designated agency), and how much of an administrative rate, if any, will be taken off at each stage? Will what is left be adequate to support people, including those with the highest levels of need?
- Will existing mechanisms be adequate to protect people from harm and to promote quality lives?

These issues and others are discussed below.

Clarity is needed on who is responsible for what for individuals who elect to manage their own money through an intermediary service organization (ISO). At the time of our study, there was both confusion and concern over who would assume liability, and who is responsible for payment of unemployment insurance and workers' compensation. At the same time, efforts were being made to clarify this through work with an outside consultant to develop the ISO idea, within the framework in which the person would be liable if his or her money goes through an ISO, and agencies would be liable if the person's money is managed by a designated agency.

There were different perspectives on this issue. For instance, agency representatives expressed concern about still having liability, but having less control. As one agency administrator remarked, "In my opinion, the state saddles us with a lot of responsibility and liability, and we have very little power in relation to our responsibilities, very little authority to change things." At least one person speculated that increased liability might encourage some agencies to be more conservative and less likely to take what they perceive to be risks. In addition, it was still unclear whether an individual would ever actually be held liable (e.g., for employee injury), versus the idea that liability would go up the chain to certified and/or designated agencies, or the state (e.g., the theory that those with the "deepest pockets" would ultimately be responsible).

Others expressed concern about the logistics of people transitioning to self-management of their money and services. It was felt that some agencies may currently

not be set up to assist people with this. Second, it was suggested, at least for some people if not many, ongoing involvement of agencies for selected services, or for occasional backup or crisis support, might be desired. Thus, for many people, there may not be a complete transition from total involvement with an agency to no involvement, and there will be need to maintain room for flexibility and negotiation around this.

Self-determination will shed light on issues related to a fair and equitable distribution of money. Generally, it was felt that a benefit of self-determination is that it will help people become more familiar with their budgets, having more information on the amount of money and more control over how the money is spent. At the same time, there still remain a lot of questions and concerns related to this.

First, as of July 1, 1998, funding decisions were to be made at the regional level, within designated agencies. However, there was widespread concern regarding the potential bias of having funders who are also service providers. People speculated that this might influence funding decisions and inhibit designated agency representatives from informing people about the full range of funding and service options.

Second, people who were interviewed felt that it would be important for people with disabilities and members of their support networks to have more clarity about what would happen to unspent money in someone's budget. Is it the person's money? If not, whose money is it, and who decides what happens to it? Related to this, people

wondered, if an individual saves money within his or her budget, will he or she have access to any of that savings? If people don't have access to any of it, what is the incentive to save money?

Third, there were concerns about financial issues in relation to people who elect to manage their own money through an ISO. It hadn't yet been decided whether the designated agencies would still take an administrative percentage if an individual decides to manage his or her own money through an ISO. If designated agencies do take a percentage, people wondered whether that would be a fixed or variable amount (e.g., across individuals, across different designated agencies) and what it would be used for. And, if designated agencies do take an administrative percentage, what will people get in return? Will any backup services be available to people? Will there be room for flexibility and negotiation in people's relationships with designated agencies? Even though large numbers of people may in fact not choose to manage their money, there was some nervousness among agency representatives about this. They felt that even the decision by one person to do so could have a significant impact on a small agency.

Finally, people wondered if budgets would be adequate to cover the various administrative and insurance expenses. Early on, it was too early to tell if this would be a problem for many people. Some people who were interviewed felt that most people's budgets would be sufficient, although at least one person had experienced a lack of money for such expenses, and some people felt there was potential for other similar situations.

Finally, people felt that it is important not to see self-determination as a cost-savings measure. They felt there is no guarantee that it will be less costly, and speculated that, in fact, there may be some costs associated with self-determination.

Quality-of-life issues need to be examined within the context of self-determination. Vermont has a good reputation for having services that are generally small-scale and more individualized and responsive in than many other states. The small size of the state has enabled people within the service system to know about and be familiar with many of those who are served by the system. This knowledge has at times facilitated problem-solving and individualized planning, and has, more generally, contributed to their capacity to focus on quality of life issues.

At the same time, some people feel that, particularly because it is a small state, there has been a high level of paternalism of the system toward people with disabilities. They suggest that many people have been too closely monitored, and perhaps have not had opportunities to take risks and make mistakes. One person commented, "When you talk about self-determination, you've got to start cutting some of those strings loose. You've got to allow some bad decisions." At the same time, one agency administrator was concerned that all of the problems will be blamed on the providers wanting too much control and not letting go, rather than recognition that everyone in the system is part of this.

It is likely that greater self-determination for some people might result in less formal monitoring by the state quality assurance review teams. Some people felt that this might put some people at risk--particularly those who do not have strong support

networks, or in case someone's support network falls apart. They do not want to see people become more isolated and at risk, in the name of self-determination. Also, some people were concerned about this potentially placing more burden back on parents, especially aging parents.

Finally, some people noted that, at the outset of the project, when teams began working with people, much of the discussion revolved around money issues. They expressed their hope that, in the long run, the project would put as much focus on relationships and other aspects of people's lives, that also contribute significantly to quality of life.

There are very limited real choices within the existing system. In different ways, many people raised issues about choice and the service system. One of the primary issues related to the limited choice of service agencies. People emphasized that this is more of a problem in some parts of the state than in others. They have different thoughts, however, on how to address this problem. Some people felt that there is a definite need to create more agencies. As one person commented, "We need to have more than just one agency as an option for people. It's not possible to create legitimate choice for everyone with one agency." Others felt that it wasn't necessarily crucial to establish new agencies; rather, it is important that: (1) existing agencies be responsive to individual needs and desires; and/or (2) people be assisted to bypass agencies and create what it is they truly want. With regard to these two options, people did feel that the increased presence of self-determination as an option will help push quality in agencies and the system as a whole, promoting increased responsiveness and

creativity. Secondly, they felt that part of the role of the project is to help people "think outside the box," and help support alternative situations, which may involve working outside and beyond the scope of agencies in many different ways.

A question that comes up related to choice is how those involved in the project would react to people's choice of things that may be harmful, isolating, or segregating. There is a sense that many people involved in the project would be upset by such choices. At the same time, however, there was a high level of agreement among people that they don't feel it is the role of the project to make any policies about this. Rather, they feel that people's support networks need to and will be a protection against this.

Finally, people expressed the need for clarification regarding what types of choices really are available for people, and what kinds of constraints, vis-a-vis the system. They talked about the need for broader education among people as to the choices and flexibility that are already available to people (e.g., through the Medicaid waiver). In addition, they talked about discovering limitations. For instance, it seems that people cannot hire anyone they want as a case manager, such as a family member, neighbor, or friend; that person has to have state certification. Also, even if the person is certified, the system isn't set up for individuals to buy workers' compensation; thus, the person may have to, in fact, become an agency employee.

Successes and Challenges

1. By mid-1998, project staff had spent much time and energy on the identification of systems barriers to self-determination, and on working to resolve these (e.g., establish the ISO, clarify insurance issues). It is important that this work went hand-in-hand with direct efforts to create alternative options for individuals involved with the project. In addition, project team members have educated themselves and begun to educate others throughout the state on existing and potential ways to create more choice and control (e.g., flexibility of waiver, ISO). At the same time, there is a broader need for people from many different constituencies to work together to continue identifying and addressing constraints to choice and control.

2. The Division and agencies in Vermont have a track record of having developed highly individualized services throughout the state. Within this framework, the Division's commitment to work toward greater control and choice by people with disabilities is reflected in its initiation of and participation in this project. In addition, from the beginning of this project, there has been some collaboration of agencies with teams and the project as a whole.

At the same time, as of mid-1998, many individuals had only recently become connected with teams and begun their pursuit of self-determination. Thus, some people were still waiting to see how the Division and agencies would respond across individual situations. Within this context, in the coming months and years, it is important that:

- agency administrators and staff be willing to collaborate with teams, families, advocates, and others to create flexible, individually tailored sets of supports, with differing degrees and types of agency involvement
- agencies be willing to listen to and respect people's requests, and to make every effort to give them adequate funding levels to meet these. The assumption should be made that people are reasonable in their requests for support and services. Asking people to make significant compromises should be the exception rather than the rule. At the same time, it was felt that agencies should recognize and appreciate people's understanding of resource limitations and their willingness to make reasonable compromises, when necessary. As one person put it, "Satisfaction doesn't just come with quantity of resources, but from how it's given out, how well people are listened to." Asking people to compromise should be the exception rather than the rule.
- the Division make every effort to give adequate compensation to agencies, which is reflective of the needs of people they support
- the Division support and recognize agencies and staff members who are flexible and creative, and actively work together with advocates, families, and others to push agencies and staff who are rigid and resistant.

3. It is important that project teams have focused on familiarizing themselves not only with disability-specific resources, but with the broader set of community resources and services that are available in the communities in their region. For the future, it will

be important for agencies, teams, people with disabilities and their support networks, and others to work together to identify and gain access to more community resources.

4. A strength of the project is that relationships and support networks are seen as playing a key role in quality assurance and safeguards, and that, as part of their role, project teams will help create or strengthen such networks for people. It is also important that those involved with the project acknowledge the need for a system role in this--one that focuses both on promoting increased choice and control, and on helping to ensure backup or crisis support, as needed.

In the future, if more responsibility for quality assurance is to reside with circles of support, guardians, families, and others, it will be important for those involved in different levels of the system to collaborate with self-advocates, self-determination project members, and others to:

- provide specific opportunities for those who are part of these circles of support to become informed about resources and options that promote control and choice
- work to diversify support circles for those who may have support circles that consist almost entirely of paid staff
- identify people who are most in need of development of a support circle.

Self-Determination Teams

A tremendous amount of effort has gone into the development of the project teams. In turn, team members have put tremendous energy into the program, and they share a common commitment and passion for their work.

The composition of the teams has been key to the project. Central to this project are four teams, each composed of a consumer facilitator, parent facilitator, and system facilitator. People felt that this design has been and will be key to the project's success. They feel it provides three perspectives on issues that come up with teams, or the project as a whole. And, they feel it gives great strength to the meetings with referrals, to have as part of the team some people who are seen as being able to relate more closely to the experiences of families and people with disabilities.

The amount of work to get the teams up and running and maintain them has been much more than anticipated. The administrative part of getting the teams up and running was a lot more work than initially anticipated. This included coordination of all the sources of project funding (the RWJ Foundation, the DD Council, and UAP). In addition, it was written into the grant that staff (except for the project coordinator and a office manager) would not be state employees. So, arrangements had to be made, and adjusted as problems arose with this, for pay to be channeled through different entities of people's choice. During initial phases of the project, this administrative work occupied significant time and energy of the project coordinator.

In addition, a challenge at the beginning of the project was to try to create a common knowledge base among a group of project staff with widely different kinds of knowledge about different aspects of the service system. Training sessions were held that not only increased common knowledge, but simultaneously offered opportunities for development of a sense of camaraderie among team members and project staff as a whole. Team members appreciated the information that was covered and found it

useful in their work. They were equally if not more enthusiastic about the team and project spirit that was evolving. For future training, they talked about hoping for more time to share among teams about strategies and resources, so each team doesn't, as one member put it, "reinvent the wheel."

There has been a high degree of clarity about the role of teams, while at the same time, there has been some confusion, disagreement, and difficulty. At the outset, it was perhaps more clear to people what roles the teams were intended not to play. For example, they were clear that they were not intended to be "service providers" or the "circle of support" for individuals involved with the project. Aside from this, the approach of the project coordinator was, within broad project guidelines, to let teams determine what the focus of their work would be, what strategies they would use, and so forth. While most team members were comfortable with this approach, others, particularly at the outset, wished for more direction from the coordinator. They did, however, appreciate that the project coordinator was in close and regular contact with them to lend support as they began meeting and formulating plans.

Over time, this combination of project guidelines and flexibility resulted in a set of four teams that do many of the same types of things, as well as some that are different. For instance, all teams meet with referrals, and act as a resource, giving information to agencies, self-advocates, family members, and other interested people. As one team member explained, "There are more myths around self-determination than could fill your notebook, particularly within agencies. And, there is literally no information out there to families and self-advocates."

They all see themselves as playing a role in developing relationships with referrals, in helping people's voices be heard, in "giving that space for the person actually to speak," and in working with them to create alternative options. They consider it equally important to help someone arrange housing, or to help them accomplish the goal of going to college, or to pursue a lifelong dream of going horseback riding. Finally, they all see themselves as doing some things (gathering information, convening meetings, etc.) that are the responsibility of various people in the system but are not getting done. For instance, in some cases, teams talked about a significant lack of face-to-face meetings between different service workers involved with a particular person.

In addition to many commonalities, some teams have chosen to place more emphasis on meeting with self-advocates than with other groups. And, some teams have chosen to focus more specifically on school/transition issues than other teams.

At the same time as there is a high degree of agreement over team roles, there has also been some confusion and disagreement over this. For instance, there was disagreement about whether a team should work with a young man, due to his age (being a minor) and due to the fact that he lives outside of his family home. However, the team chose to continue working with him. There has also been some confusion and disagreement over the degree to which team members should advocate on behalf of people who they are working with.

Finally, one of the most difficult aspects of the team work is the amount of travel involved, and thus the amount of time spent traveling versus doing other tasks. There

was almost unanimous agreement that the amount of travel is difficult, accompanied by suggestions that there should perhaps be six teams, or one team that is mobile, or more hours of work.

Team building takes significant time and effort. Project staff have found that the process of team building takes time and work, and that this process worked differently from one team to another. Teams members felt they received significant support for team building from non-team project staff. At the same time, non-team project staff were very respectful of the work involved in building teams, as well as the unique process of team building from one team to another, and did not make comparisons among them. Sometimes, it was members of teams themselves who perhaps did not give themselves sufficient credit for all the work that went into team building and compared themselves to other teams, feeling as though they hadn't accomplished as much work if they hadn't handled as many referrals.

Various challenges arose for teams in the dynamics of including the consumer facilitator in working as a team of equals. Some of the challenges related to assisting consumer facilitators to do the team work were addressed through the project's hiring of a support person for the consumer facilitators (this is discussed more below in the section on support of consumer facilitators). This need was identified and addressed shortly after the project began.

Other challenges have been dealt with by the teams themselves, with support from non-team project staff. All teams have had to work on ways of including the consumer facilitator--for instance, when the other two team members tended to be

talkative, they had to learn to build in opportunities for the consumer facilitator to have a chance to speak. Some team members had to work on ingrained stereotypes which made it hard for them to conceive of the consumer facilitator as capable of participating on such a team. One team member reported, "At first I didn't see how he (the consumer facilitator) could do the job." However, this team member indicated that he had learned a lot about how this person could participate over the first months of the project. Finally, some team members were at first tempted to "fix" the life of the consumer facilitator on their team. They needed reminders from others that this was not the purpose of their team.

Overall, all team members agreed that consumer facilitators are equally valuable, key players on the teams, and that it has been a tremendous learning experience as they have all learned from each other as they have worked together.

It has taken some time to figure out how best to support the consumer facilitators as team members. Since the beginning of the project, project staff have been working to try to figure out how best to support the consumer facilitators on the teams.

Just after the project started, it was recognized that there would be a need for a staff person responsible for support of consumer facilitators. This person has assisted with everything from establishment of in-home offices and technical things such as time sheets, and other paperwork, to supervision of job coaches and contact with their supervising agencies, to assisting with team dynamics and inclusion of the consumer facilitator. While it has been positive having this position, the down side is that some

people then come to rely on this one person to deal with everything related to the consumer facilitators.

Problems have also occurred with the people who were hired to support the consumer facilitators. During our interviews, these problems were not identified by consumer facilitators, but were identified by a number of non-consumer project staff. These include:

- The support people were all employed by different agencies, which had different approaches to staff training, roles, responsibilities, and so forth. Some project staff suggested that it would be easier if all support people were instead employed by the project itself.
- Some of the support people were trained as job coaches, whereas others were not. Project staff felt that a "job coach" orientation, with an emphasis on working toward increased and maximum independence, was best suited to the project. Project staff were wary of some support people who seemed to "take over" and speak for the person, or speak instead of the person, at team meetings, and were working to address these issues with the consumer facilitators and their support people.
- Consumers facilitators, and their support people, used almost all of their project hours in meetings and travel. This leaves little time for support people to assist consumers in doing preparation and follow-up work in the home office.

Finally, there has been some lack of family support for consumer facilitators to participate. In some cases, this has involved lack of family understanding about how their member with a disability could make a valuable contribution to such a project and could do work that was worthy of the salary they were earning. In one case, however, the lack of family support for participation led to the withdrawal of one consumer facilitator.

Successes and Challenges

1. It is positive that teams have begun to cultivate positive working relationships with some agencies, working collaboratively on individual situations. Over time, it may be challenging, but essential, for teams to continue to cultivate positive relationships with designated agencies--relationships that include room for collaboration as well as advocacy. Most cases will likely be more collaborative than contentious, with the teams serving as a resource both for people with disabilities and their support networks and to agencies, and with agencies serving as a resource as well. At the same time, there may be situations which call for team advocacy on behalf of a particular person vis-a-vis an agency. Such advocacy could be undertaken with discernment from a broader group of people. And, it will hopefully occur within the context of a broader, cooperative relationship between team and agency.

2. A great strength of the project has been the formation and coalescing of the teams. Many things have contributed to this. Project staff have worked hard to organize, develop, and support the teams. Team members have worked hard to develop ways of working together, of educating themselves, and of beginning to do

outreach to others. As time goes on, and teams gain more experience working on individual situations, it will be important for team members, and all project staff, to have more opportunities to share experiences, brainstorm about problems, and celebrate successes. As one person put it, "I would like to have more sharing and access to the creative minds of the other teams."

3. Another great strength of the project is the commitment to this work by all project staff. Team members have been very committed to working together, giving voice to people who haven't been heard, and helping create real alternatives for people. Other project staff have been very committed to supporting the teams, and to supporting the broader work on the project.

Based on their developing commitment to the people they are working with, teams have begun to develop significant relationships with those people. As this relationship evolves, a challenge will be for the teams to continue to play the originally conceived team role, rather than that of "advocate," and at the same time honor the depth and importance of the relationship to the person. And, based on the commitment of all staff to the project, they have traveled extensively and worked long hours, many above and beyond paid project time. As the project continues, it will be important to brainstorm ways to maintain positive energy over the long term.

4. Finally, a great strength of the project has been support of consumer facilitators. The project has put time, energy, and financial resources into this effort, both from the outset and in response to lessons that have been learned since the project began. Consumers facilitators are regarded as key, crucial members of the

teams. As one person commented, "It's totally clear that the consumers contribute as much as any other team member." In order to maximize the contributions of consumer facilitators, further priority must be placed on giving support to consumer facilitators within their home offices. Such support must be seen as equally as important at tasks outside the home, and as crucial to full participation in the project.

Conclusion

The Vermont Self-Determination Project was designed to promote systems change, in order to increase the likelihood the self-determination would not just be a "hit or miss" opportunity for people. The intent, however, was to not just work on changing the system in isolation, but to do so while at the same time working with individuals to create real change in their lives.

By mid-project, one of the key lessons was about how much effort is required to make such comprehensive systems change. Some of the necessary changes were anticipated; others were identified based on beginning work of the project with various individuals. There are short-term tradeoffs to such work on systems change. The energy and resources put into work on systems change at times seems to take energy and resources away from the work of helping create individual change. At the same time, the work to change the system helps ensure that the opportunity for increased choice and control is substantial and lasting.

It is also key that the need for significant collaboration was recognized. Such collaboration is challenging, calling for the willingness and hard work from everyone of

forging new roles and relationships, so that people with disabilities become true collaborators in the design and implementation of a new system, not just the recipients.

Within the Vermont Self-Determination Project, collaborative work at the systems and individual level has begun to create significant change within the system and in individual lives. Continued work along these lines will be the key to solidifying the foundation for self-determination--real choice and control for people with disabilities. As this continues to happen, self-determination will no longer be just a "hit or miss" program that occurs in small pockets, but will become a force that helps transform people's lives and at the same time helps transform the system and its role in people's lives.